



# ART Adherence in Adolescents

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# Context: Why Focus on Adolescent Adherence?

- **Renal transplantation:** 35% lost graft within 36 months of transfer  
*Watson A, 2000*
- **Congenital heart disease:** 1 in 5 deaths “avoidable”  
*Somerville J 1997*
- **Diabetes:** 10-69% no medical follow up after paediatric care  
*Pacaud D et al, 1996, Frank M 1996, Kipps S et al, 2002*
- **HIV:** adolescents are less adherent to ART; have lower rates of virologic suppression and immunologic recovery and a higher rate of virologic rebound after initial suppression  
*Nachega JB et al, 2009*



# Context: Why Focus on ALHIV?

- Young people aged 10 - 24 represent at least a quarter of the world's population, but are disproportionately affected by HIV  
*(WHO, 2009; Idele P, Gillespie A, Porth T et al, 2014)*
- Although the rate of new HIV infections has declined in many populations, over a third of new HIV infections occur among the 15 to 24 year age group  
*(Kasedde S, Kapogiannis BG, McClure C, et al.2014)*
- Southern Africa is at the epicentre of the global HIV epidemic, with almost 40% of the global burden of infection despite being home to less than 2% of the global population  
*(UNAIDS, 2013)*
- Worldwide, HIV/AIDS and depression are the leading causes of disease burden for young people aged 10–24 years  
*WHO, 2001)*

# New Infections in Adolescents and Youth

**TABLE 2: Twenty sub-Saharan African countries with the most new HIV infections among young people aged 15–24, 2009**

Country	Total	
	Estimate	[low estimate - high estimate]
South Africa	160,000	[140,000 - 190,000]
Nigeria	120,000	[110,000 - 140,000]
Mozambique	49,000	[41,000 - 56,000]
Uganda	46,000	[38,000 - 53,000]
Kenya	42,000	[27,000 - 56,000]
United Republic of Tanzania	40,000	[31,000 - 52,000]
Zambia	27,000	[22,000 - 32,000]
Malawi	26,000	[18,000 - 33,000]
Cameroon	22,000	[18,000 - 25,000]
Zimbabwe	22,000	[14,000 - 31,000]
Lesotho	9,400	[7,900 - 11,000]
Ghana	8,300	[6,300 - 10,000]
Angola	8,000	[5,400 - 11,000]
Botswana	6,000	[4,300 - 8,800]
Chad	5,900	[3,700 - 21,000]
Swaziland	5,600	[4,600 - 6,600]
Côte d'Ivoire	5,200	[2,600 - 9,100]
Burundi	4,300	[3,200 - 5,100]
Togo	4,000	[2,300 - 5,800]
Rwanda	3,700	[1,400 - 6,600]
World	890,000	[810,000 - 970,000]

Source: UNAIDS unpublished estimates, 2010.

Young people aged 15 – 24 account for 41% of all new adult infections (aged 15 years and older) in 2009.

In 2009, an estimated 2500 young people aged 15 – 24 were infected every day for a global total of 890,000 [810,000 – 970,000].

Nearly 1 in every 3 in South Africa and Nigeria

80% in sub-Saharan Africa

6% in South Asia

5% in Latin America and the Caribbean

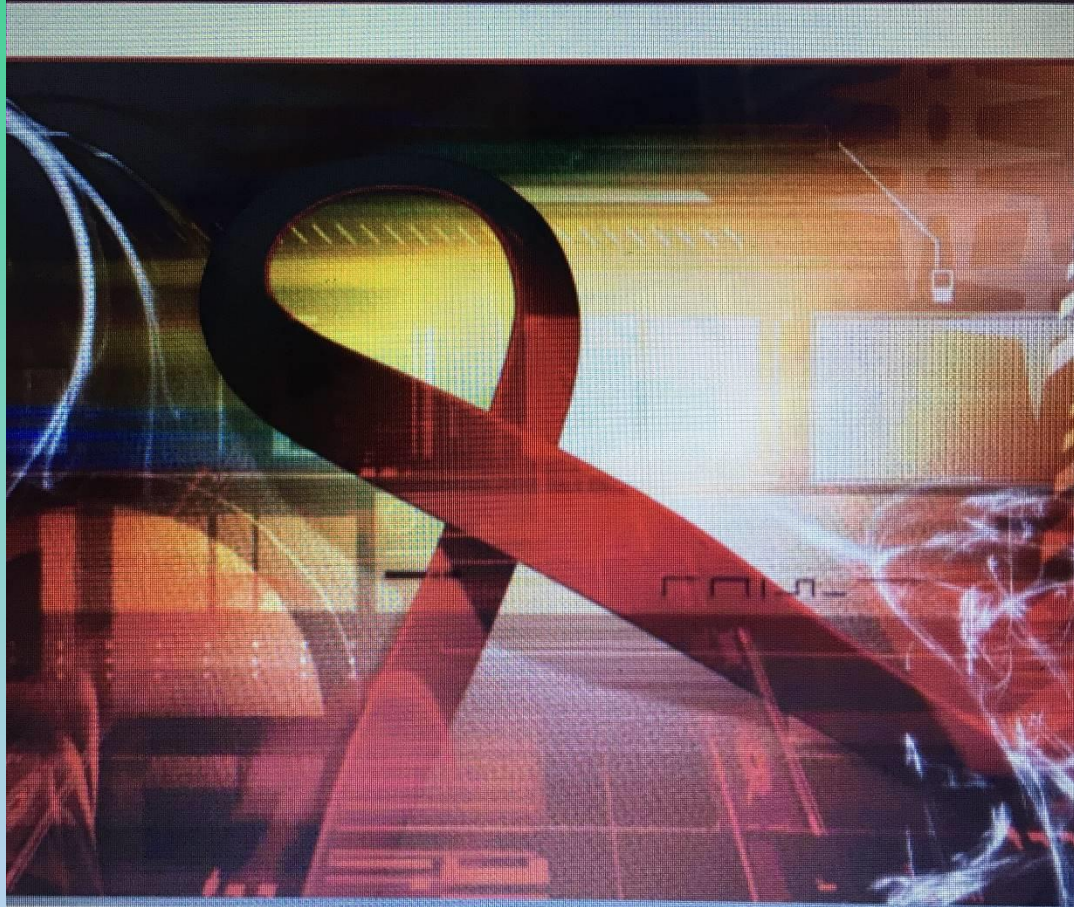
4% in East Asia and the Pacific

3% in the Middle East and North Africa

2% in Eastern Europe and Central Asia



# Adherence to antiretroviral therapy in adolescents and young adults



A publication of the Southern African HIV Clinicians Society



# Common Challenges for ALHIV

- Stigma and discrimination
- Issues related to disclosure (intimacy vs isolation)
- Chronic illness, may have comorbidities (adolescents with a prior AIDS-defining condition are less likely to survive to an older age)<sup>1,2</sup>
- Loss of autonomy/independence
- Control vs uncertainty

1. Dollfus C, Le Chenadec J, Faye A, et al. **Long-term outcomes in adolescents perinatally infected with HIV-1 and followed up since birth in the French perinatal cohort (EPF/ANRS CO10).** *Clin Infect Dis.* 2010;51(2):214–224

2. McConnell MS, Byers RH, Frederick T, et al. **Trends in antiretroviral therapy use and survival rates for a large cohort of HIV-infected children and adolescents in the United States, 1989–2001.** *J Acquir Immune Defic Syndr.* 2005;38(4):488–494



# Adherence Preparation

- ARVs are seldom an emergency
- Adequate preparation time is never time wasted
- ART education/treatment literacy
- Individual assessment of readiness
- Identified supporter/caregivers - > 1 desirable
- Joining a support group also desirable



# Adherence Preparation Cont ...

- Advise that it takes time to get used to ART
- Know the common side effects and prepare mentally for them
- Develop a routine...work ARV's into your routine
  - **Near toothbrush**
  - **Near bed**
  - **In school/work bag**
- Develop good practices
  - **Take ART with you on day outings**
  - **Take ART with you for weekends**
  - **Never run out of supply at home**
  - **Plan for extra ART if you are going on holiday/going home**
- Seek and accept support from healthcare staff, CBOs, family and friends





# Predictors of Adherence in Adolescents

- Related to age and developmental level
- Impact of peer groups
- Relationships with family and community
- Current health status
- Family health
- Previous experiences of taking medicines
- Preferred cultural modes of healing
- Awareness of reasons for taking medication
- Relationships with healthcare staff



# Challenges to Adherence

Many challenges with adolescent HIV treatment remain, and often place this age group at risk for failing their treatment

The treatment failure rate for adolescents with HIV is much higher than that of adults

Whereas the failure rate for adults ranges from 10% to 15% depending on location, failure rates for adolescents are reported to be as high as >50% in some studies

Salou M, Dagnra AY, Butel C, et al. **High rates of virological failure and drug resistance in perinatally HIV-1-infected children and adolescents receiving lifelong antiretroviral therapy in routine clinics in Togo.** *J Int AIDS Soc* 2016.

Solutions to these challenges for this vulnerable population should be a priority, given a 50% reported increase in AIDS-related mortality relative to a 30% decline in the general population

**Differentiated care: Relevant globally, urgently relevant in sub-Saharan Africa. It's time to *deliver* differently.**  
[http://www.differentiatedcare.org/Portals/0/adam/Content/yS6M-GKB5EWs\\_uTBHk1C1Q/File/Decision%20Framework.pdf](http://www.differentiatedcare.org/Portals/0/adam/Content/yS6M-GKB5EWs_uTBHk1C1Q/File/Decision%20Framework.pdf) (accessed 1 May 2017).

# Factors Influencing Adherence

Correlates exist between ART adherence among adolescents in low and middle-income countries and the following:-

- Gender and knowledge of HIV status
- Influence of family structure (orphan, loss of parental support)
- Impact of onerous ART regimens
- Attitudes about medication
- Healthcare challenges
- Environmental factors (such as rural v urban setting)
- Retention in care (RIC)
- Lack of autonomy (reliance on caregiver to access care)
- Compliance with clinic visits
- Collection of medication
- Adherence to dosing schedules

# Delays in ART Initiation

- Additional education required
- Not accepting of diagnosis/unwilling to take ART
- Non disclosure/no supporter
- Lack of supporter commitment
- History of irregular clinic attendance
- Acute illness
  - Treat/stabilise first where possible to avoid IRIS/  
treatment overload



# Principles of ART for ALHIV

- Use fixed-dose combinations (FDCs) as far as possible; e.g. Atripla (EFV/FTC/TDF) or equivalent when weight >40 kg and glomerular filtration rate (GFR) is normal
- Combined drugs such as ABC/3TC, AZT/3TC, TDF/FTC are preferable where possible instead of single drugs
- Aim for a once daily regimen; e.g. Aluvia (lopinavir/ritonavir – LPV/r) and ABC/3TC can be given once or twice daily, but should be given once daily when possible
- Regimen simplification can assist in improving adherence by reducing pill burden and/or dosing schedule
- Unfortunately this may be more difficult if an ALHIV develops resistance mutations and moves to second/third line regimens





# Assessing Adherence

HIV VL monitoring is the most accurate assessment of adherence, but it is expensive and frequency is governed by guidelines

Accurately assessing adherence is influenced by many factors, but the most critical is HCW/ALHIV relationship

If a positive relationship, ALHIV will be more willing/able to discuss adherence challenges

This may offer the opportunity to intervene before treatment fails/resistance develops

**Think about HOW you ask the questions:-**

Have you missed any doses in the last month?

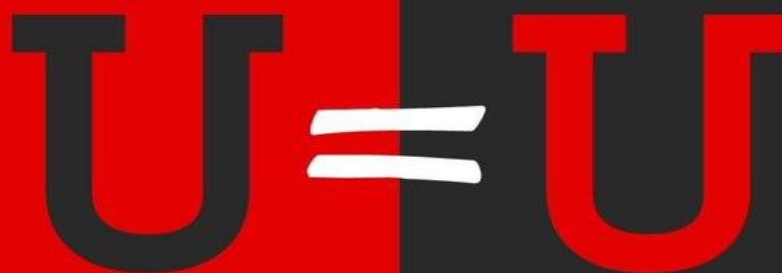
**OR**

How many doses have you missed in the last month?

# Promoting Adherence

**What other messages can we communicate to promote adherence in ALHIV?**

- For younger (perinatally infected) adolescents, the opportunity to move to FDC once >40kg can motivate adherence
- For older (perinatally or behaviourally infected) adolescents, understanding risk of onward transmission (sexual partner(s) and EMTCT) can promote adherence



**Undetectable = Untransmittable**

**It's a fact...**

"a person living with HIV who has an undetectable viral load will not pass HIV to their sexual partners."

The Saving Lives charity is proud to support the Prevention Access Campaign's UequalsU consensus statement



# Support for ALHIV

A crucial aspect for adherence support is the availability of peer support

## Key considerations

- **Group composition:** Considerations when creating support groups for ALHIV include:-
  - Age
  - Gender
  - Learning ability/disability
  - Disclosure status
  - Perinatal/behavioural HIV transmission



# Support for ALHIV Cont...

Counsellors, nurses, health promoters, psychologists, social workers or peer educators as facilitators – consider preference of group

**Possible topics:** Topics to be relevant/age appropriate  
Include topics requested by ALHIV in the group where possible

- Broad life skills, including communication, negotiation and mitigation
- Comprehensive sexuality education (CSE)
- Family planning (including contraceptive choices)
- Employment/career planning
- Importance of educational attainment

# Healthcare for ALHIV

## Adolescent and youth-friendly services (AYFS)

- Effective adherence support needs to take place within the context of services that are sensitive and responsive to the needs of ALHIV
- Young people face many barriers in accessing healthcare, especially sexual and reproductive health (SRH) and HIV services
- These challenges are exacerbated for ALHIV
- Barriers affect service utilisation, access to support, RIC and adherence to treatment
- Ensuring clinics are adolescent friendly is essential if ALHIV are to remain engaged in treatment and care



# What do Adolescents Want in a Clinic?

- “We need accessible clinics with non-judgmental, friendly staff and short waiting times”
- “Most important when choosing a clinic is staff attitude, location, atmosphere, contraceptive methods available and clinic hours”
- “A friendly environment where we can hang around not only because we sick, but as a health information centre”



# Services for ALHIV Cont...

- Confidentiality, respectful treatment, integrated services and easy access are all essential components
- Staff attitude is critical. Knowledge, personal views, attitudes and behaviours, as well as clinic practices are potential barriers to their ability to be responsive to the needs of ALHIV

Services also need to consider additional issues affecting some ALHIV, including:-

- Those who are pregnant or parenting
- Sex workers
- Sexual assault survivors
- Key populations, including lesbian, gay, bisexual, transgender, intersex and questioning (LGBTIQ); disabled; homeless; displaced; and other special needs ALHIV

# AYFS

## Key components of adolescent and youth friendly services include:-

- AYFS training/orientation needs to be provided to all healthcare providers and other cadres of staff
- Opening hours need to accommodate school going youth
- Youth-friendly sessions can be integrated into mainstream services. It is helpful to have dedicated sessions for adolescents (Happy Hour), and if possible, separate youth-friendly areas in the clinic.
- Peer educators can put young people at ease and assist navigation of services
- Views of ALHIV concerning their experiences and potential areas for improvement should be regularly sought
- Services should be designed to provide integrated care, including HIV and SRH services

# Mental Health and ART Adherence

- Mental health disorders are defined as clinically significant behavioural or psychological impairment(s) of an individual's normal cognitive, emotional or behavioural functioning, associated with present distress and being caused by physiological or psychological factors
- Mental health disorders commonly start in adolescence between age 11 and 18 years, with depression and anxiety contributing the largest burden in this age group
- Despite recognition of the impact of mental health disorders, these receive relatively little attention in adolescents, and are frequently under-diagnosed and under-treated, as routine screening is seldom conducted as a standard aspect of care



# Mental Health and ART Adherence Cont...

- Negative health and social outcomes include adolescent pregnancy, dropping out of school, and substance abuse
- Within families, under-reporting is common as mental health difficulties are often feared or misunderstood or attributed to normal adolescent behaviour
- For an ALHIV, the detection of mental health issues is of particular importance if adherence is to be achieved and maintained
- Mental health screening has now been incorporated into standard PHC and is monitored in Ideal Clinic and AYFS





# Mental Health and ART Adherence Cont...

- Neurocognitive and mental health disorders can and do play a significant role in health outcomes
- Perinatally infected adolescents present with particularly high rates of emotional, behavioural and psychiatric disorders, exceeding rates in the general population and in other high-risk groups
- In the context of HIV, the impact of mental health on treatment adherence is a serious concern: poor adherence increases the risk of HIV treatment failure and drug resistance, progressively limiting future ART options and increasing morbidity/mortality

# Mental Health and ART Adherence Cont...

**Other disorders will negatively impact on adherence if not effectively diagnosed and managed.**

**Common mental health problems are seen disproportionately in ALHIV. These include:-**

- Generalised anxiety disorder
- Panic disorder
- Post-traumatic stress disorder
- Substance abuse disorder
- Attention deficit hyperactivity disorder



# Neurocognitive Function and ART Adherence

Impairments in cognitive function also negatively impact on ALHIV. These include:-

- Attention
- Memory
- Producing and understanding language
- Learning
- Reasoning
- Problem solving
- Decision-making

Milder forms of neurocognitive disturbance are recognised in ALHIV, including milder forms of the HIV-associated neurocognitive disorders (HANDs) seen in adults



# Neurocognitive Function and ART Adherence

Neurocognitive difficulties in ALHIV are often overlooked, but can have implications for functioning at various levels including academic performance and ART adherence

Although initiation on ART has been shown to improve cognitive functioning - particularly if ART is started early - ALHIV may present with deficits in specific areas that may have implications for health literacy and adherence as they move towards taking more responsibility for their healthcare

World Health Organization (WHO). **Adolescent development**. Geneva, Switzerland: WHO, 2016. [http://www.who.int/maternal\\_child\\_adolescent/topics/adolescence/dev/en/](http://www.who.int/maternal_child_adolescent/topics/adolescence/dev/en/) (accessed 28 November 2016).

Thus many ALHIV in South Africa today are at risk of neurocognitive challenges due to ART availability >15 years ago

# Models of Care for ALHIV

- The ability to provide services that are tailored to the specific needs of ALHIV (differentiated care) has particular relevance to ART adherence
- Sustained adherence, often from early childhood through adolescence into adulthood, is essential to reduce
- To date, focus has been placed on DSD models for adult patients who are stable on ART
- Adolescent outcome studies report sub-optimal adherence and poorer outcomes than their adult counterparts and should thus be prioritised for differentiated models of care





# Key Populations: Pregnant ALHIV

## Supporting pregnant ALHIV

It is important to gain or retain pregnant adolescents in care during this challenging time for pregnant or new young mothers, who will have to attend the clinic more frequently with healthcare visits for infants as well as herself

Where possible, retain the pregnant adolescent in current care model, but ensure that she attends for ante-natal and post-natal care and infant follow up

Identify parenting support groups and other support opportunities available in the community (M2M)

# Pregnant ALHIV Cont...

ART adherence presents a significant challenge for pregnant AYLHIV. Studies examining age as a variable in ART adherence in pregnancy have consistently found a negative association with younger age (<25 years old)

Fatti G, Shaikh N, Eley B, Jackson D, Grimwood A. **Adolescent and young pregnant women at increased risk of mother-to-child transmission of HIV and poorer maternal and infant health outcomes: A cohort study at public facilities in the Nelson Mandela Bay Metropolitan district, Eastern Cape, South Africa.** *S Afr Med J* 2014;104:874

Horwood C. et al. **HIV-Infected Adolescent Mothers and Their Infants: Low Coverage of HIV Services and High Risk of HIV Transmission in KwaZulu-Natal, South Africa.** *PLoS One* 2013;8:e74568

Nachega JB, **Antiretroviral therapy adherence, virologic and immunologic outcomes in adolescents compared with adults in southern Africa.** *J Acquir Immune Defic Syndr* 2009;51:65-71

- Compared with their older counterparts, pregnant ALHIV have poorer outcomes, including:-
  - An increased risk of MTCT
  - Poorer maternal outcomes
  - Poorer infant outcomes



# Pregnant ALHIV Cont ...

- There is increased stigma associated with teenage pregnancy, in addition to high losses to care especially after delivery
- Frequently, pregnant teenagers are no longer regarded as adolescents eligible for adolescent services
- Pregnant adolescents are commonly denied access to education, reducing their opportunities for future career/employment opportunities
- Transferring pregnant teenagers to alternative (adult) clinicians may increase risks of poor adherence to ART and RIC
- Pregnant ALHIV require specific considerations and services in order to support ART adherence and good health throughout pregnancy and the postpartum period



# Pregnant ALHIV Cont...

## CONFIDENTIAL TEENAGE PREGNANCY MANAGEMENT RECORD

### OBJECTIVE

Pregnancy during teenage years poses an increased risk of adverse outcomes for both the mother and baby. These include premature delivery, gestational diabetes, anaemia, small for gestational age and low birthweight infants, increased neonatal mortality and pregnancy-induced hypertension.

To improve outcomes for pregnant teenagers and their babies, this record should be completed at the first appointment and used in addition to standard antenatal management records.

NAME:		SURNAME:	
DOB/ID:		CELLPHONE:	
AGE:	(Increased risk if < 16 years) <b>RISK?</b>	DATE:	
<b>CLIENT HISTORY</b>			
PREGNANCY:	PLANNED <b>UNPLANNED</b>	Estimated Gestation: (Increased risk if >20 weeks at booking)	<b>RISK?</b>
First pregnancy? (Comments)	HIV Status: <b>+VE</b> -VE <b>NOT KNOWN/DECLINED</b>		
	If +ve, in EMTCT Programme? YES <b>NO</b>		
<b>RISK FACTORS</b>			
Who do you live with? (circle all)	PARENT(S)	PARTNER	EXTENDED FAMILY OTHER
How many people in your home?			
How many people working?	Increased risk if low percentage working <b>RISK?</b>		
Anybody smoke at home?	<b>YES</b>	NO	
Any alcohol/drug issues at home?	<b>YES</b>	NO	
Are you at school/college/working?	YES	<b>NO</b>	
Are you planning to return after the birth?	YES	<b>NO</b>	
How old is the baby's father?	Increased risk if >5 years older than client OR <18 years <b>RISK?</b>		
What is your relationship status?	MARRIED	COHABITING	<b>SINGLE</b>
Is the baby's father supportive?	YES	<b>NO</b>	NOT KNOWN
Any violence in the relationship?	<b>NOW</b>	NEVER	<b>SOMETIMES</b>
Are those you live with supportive?	YES (Who?)	<b>NO</b>	

# Key Populations

- There is increasing focus on the needs of key adolescent populations including sex workers, MSM, LGBTIQ and people who inject drugs (PHID)
- This focus extends to other adolescents with increased vulnerabilities, such as those who are disabled, orphaned, part of child-headed households, homeless, sexually abused or exploited, or in correctional institutions or care homes
- HIV prevalence is higher in key populations than in the general population because of less access to services/information and commonly engagement in higher risk behaviours
- Legal and social issues also render these populations more vulnerable due to discriminatory laws and policies, stigma and prejudice, with associated barriers to accessing health services



# Key Populations Cont ...

PLHIV from key populations face stigma, exclusion, harassment and violence on two fronts: because of their HIV status and because they are from a key population

Despite the number of new HIV infections occurring in these populations, they often have the least access to prevention, treatment, care and support

It is important to consider which models of care can work with support services for specific key populations in order to maximise opportunities for ART adherence

It is also important to consider which support groups are available and most appropriate to meet their additional needs



# Key Populations Cont ...

Like ALHIV, key populations are not homogenous; their individual needs must be assessed

Aspects to consider for individualised models of care include:

- Quick community/facility ART refill pick-up
- Support from specific key population-sensitised services
- Access to mobile services for specific key populations
- ART refills from pick-up points
- Support groups specifically tailored to their needs
- Referral to specialised support partners/agencies

Regardless of models of care available, sensitisation and capacitation of healthcare providers should be provided to improve treatment adherence and RIC



# Key Populations Cont ...

## **Supporting ALHIV with disabilities**

ALHIV with disabilities face ongoing challenges with disclosure and in accessing HIV counselling and treatment services. Reasons for this include:-

- Disabled persons are stigmatised generally and may not seek medical assistance
- Healthcare providers are not trained to work with persons with disabilities, may lack knowledge about disability issues, or have misinformed attitudes towards such persons
- Healthcare providers often feel overwhelmed when managing an adolescent with a disability
- Services offered at clinics, hospitals and other locations may be physically inaccessible, lack South African Sign Language (SASL) interpreters, or lack information in alternative formats such as Braille, audio or easy-to-understand language



# Key Populations Cont ...

- In settings with limited ART persons with disabilities may be considered low priority for HIV testing and treatment given the limitations already highlighted
- Health professionals may not pay enough attention to the potential for negative drug interactions between ART and the medications that persons with disabilities are taking
- Some medications may actually worsen the health status of persons with co-morbid health conditions such as depression
- Consider how the frequency of clinic visits can be reduced, ie engaging CBOs or ward-based outreach teams (WBOTs) for home delivery of ART refills

# Key Populations Cont ...

- ALHIV with disabilities are often already isolated. It is therefore important to identify support groups or after-school programmes that they may access
- It is important to explore whether they are comfortable with being included in general ALHIV group, or whether there is a need for separate services adapted to their needs
- Provide suitably adapted treatment literacy tools, where possible
- Include training for professionals that includes rights and sensitisation to the respective needs of different disabilities
- Provide adequate HIV training and support for personal assistants, SASL interpreters and other people who support persons with disabilities, with a particular focus on rights and confidentiality

# Long Term Adherence for ALHIV

- Lifelong adherence is a complex and difficult task
- May become increasingly difficult as the years pass by; adolescents a common time of challenges
- Identify and reinforce effective strategies (e.g. support groups, disclosure to family, friends etc)
- Often related to levels/timing of disclosure and adolescents; later disclosure leads to more issues

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